

# LE CHILDREN NEWSLETTER \*

MAY 2017

"WE HAVE BEEN ON THE RECEIVING END OF SO MUCH GRACIOUSNESS, CARE AND LOVE."

**Stefania** 2016 Radiothon participant

## HAVE YOU EVER RECEIVED SO MUCH LOVE THAT ALL YOU WISH FOR IS TO GIVE BACK?

At this time last year, my husband and I were getting ready to share our story on the *Caring For Kids* Radiothon as a way of thanking those who had saved our Sofia. We knew since pregnancy that our baby would be born with Truncus Arteriosus, a rare congenital heart disease where the pulmonary and aortic arteries fail to separate and adequately develop. We were told she would need surgery a few days after birth, but when that day arrived, it was a battle between emotion and reason.

It's hard to explain. Even though you have been "prepared" for it, you never really are: there's always that pull, a sentiment that goes against your maternal and paternal instincts. However, it was a life or death situation and we put all our trust in the Children's.

The open-heart surgery went well and Sofia stayed at the Children's for almost two months. We will never forget how dedicated her care team was, you could just tell their hearts were in everything they did. She's now closely followed by the cardiology team because of arrhythmias. In the past 18 months, the genuine and compassionate way that the staff treats children and parents has accompanied us on this journey.

It's that culture that encouraged us to share our story with people like you. Your generous support helped make our journey so much easier. Our daughter will need several surgeries before adulthood, including one possibly in the coming months.

WE ARE GRATEFUL TO HAVE THE CHILDREN'S AND DONORS LIKE YOU BY OUR SIDE. PLEASE TUNE IN TO THE RADIOTHON ON MAY 31ST AND IF YOU CAN, HELP IT GET OFF TO A GREAT START BY DONATING TODAY.

- Stefania Sofia's mom

# What You Helped Accomplish

Because of you, the financial year that just ended was a resounding success! Your generosity made it possible to undertake innovative projects that are vital to the wellbeing of our patients. Below are two wonderful examples of how invaluable your help has been:

#### THE PROCEDURE ROOM

No one likes to see a child suffer. Pain management is crucial, because children who experience pain as a result of an intervention will suffer both immediate and long-term consequences. There is now a way to alleviate this stress for our young patients and their parents. Thanks to your support, they now have access to a fully equipped modern sedation room with trained staff dedicated to managing their pain, from pre-sedation to recovery.

The importance of the procedure room is evident in the appreciation shown by one of Samson's caregivers who experienced it first hand:

"Samson is non-verbal and diagnosed with Autism Spectrum Disorder. The availability of such a procedure room is paramount in the investigation and treatment of special needs clients. The process of elimination is very challenging, to discover whether there are physical causes and/or triggers for Samson's recent increase in episodes of agitation and/or aggressive behaviour. We are so grateful."

#### **GENE TESTING IS HERE**

Imagine you have a child with a health problem no one can identify. You are told it may be a genetic disorder but the only way to know for sure is through innovative DNA and RNA testing. And those genetic tests need to be done in the U.S. This is about to change, thanks to your support.

Child Health Research at the MCH is repatriating some of the technologies of next generation sequencing (NGS) so that tests can be done at the Glen site. Thanks to your generosity, children with respiratory diseases, rare pediatric cancers and brain malformations notably will benefit from state-of-the-art diagnosis tools. These can confirm a diagnosis, assist in determining a prognosis, lead to genetic counselling and in a growing number of cases, offer a choice of personalized treatments.

Thank you for helping the Children's remain at the forefront of pediatric care and research!

Did you know that even teddy bears can require surgery?! Children waiting for surgery, like little Sawsan (A), were treated to a Teddy Bear Clinic by the Child Life Services. This program is designed to help kids reduce anxiety associated with an upcoming operation.

The kids who celebrated their birthdays by asking for donations to the Children's in lieu of gifts got a very big reward. From magic tricks (B) to a funny photo booth (C) and arts and crafts, nearly 60 members of the Young Ambassadors' Club and their families enjoyed events organized just for them in the P.K. Subban Atrium, all in celebration of the joy of giving.



## HOW WELL DO YOU KNOW THE CHILDREN'S?

1. WHAT IS THE NAME OF THE CHILDREN'S MASCOT?

. . .

2. WHAT PERCENTAGE OF THE HOSPITAL DOES THE NEONATAL INTENSIVE CARE UNIT OCCUPY?

. . .

3. WHAT PERCENTAGE OF FRANCOPHONE PATIENTS ARE CARED FOR AT THE CHILDREN'S?

Find out how well you scored at childrenfoundation.com/quiz/

## LÉA-MARIE: The Fight of Her Life



#### LÉA-MARIE IS JUST 12 YEARS OLD AND SHE ALREADY HAS HER OWN CONDO:

"A corner unit with large windows, a super comfortable bed and Wi-Fi," she explains with a sly smile as she gets into her bed on the 7th floor of the Children's. Léa-Marie has a rare and serious disease that, for the last year and a half, has forced her to call the Children's her second home.

It all started in November 2015, when her greenish complexion and a lack of energy led her parents to bring her to the Children's. Léa-Marie's mother Sophie remembers comforting her by saying: "You're going through a stressful time, with your high school entrance exams and cross-country ski competitions coming up." They never expected she would be diagnosed with aplastic anemia, a disease that prevents the body from producing red blood cells.

Léa-Marie began her treatment at the hematology clinic three to four times a week, but after a few months, her condition hadn't improved. She needs a bone marrow transplant, and her immune system has to be destroyed for the transplant to succeed. She can't walk for more than a few minutes at a time, and the medications have swollen her face to the point that the pre-teen doesn't recognize herself.

ON TOP OF BEING ISOLATED FROM HER FRIENDS, LÉA-MARIE HAS DEVELOPED NEW FEARS. SHE CAN'T FALL ASLEEP IF SHE'S ALONE. "I AM SO GRATEFUL TO MY LITTLE SISTER FOR SPENDING SO MANY NIGHTS WITH ME," SHE SAYS, FIGHTING BACK TEARS.

When discussing what's toughest about her disease, Léa-Marie explains: "It's not the needles! You never really get used to them but it's part of the routine. The hardest part is not being able to go to school. I was so sad when they told me I couldn't go. To me, it meant I couldn't live a normal life anymore."

SEE HOW LÉA-MARIE IS COPING WITH HER DISEASE NOW: childrenfoundation.com/blog/leamarie

## **RESEARCH:** An Allergy Game-Changer



#### WHAT IF THERE WAS A PREVENTIVE TREATMENT THAT COULD IMPROVE THE QUALITY OF LIFE FOR COUNTLESS CHILDREN WHO SUFFER FROM SEASONAL RESPIRATORY ALLERGIES?

How about a vaccine that could prevent an allergic reaction to tree pollen? Dr. Christine McCusker, Pediatric Allergy Division Head at the Montreal Children's Hospital, is working to develop the treatment.

#### DR. MCCUSKER SAYS THE VACCINE SHE'S WORKING ON COULD HELP 30 % OF THE POPULATION, INCLUDING CHILDREN LIKE 9-YEAR OLD ALEXA AND HER BROTHER, 11-YEAR OLD MACKENZIE.

The two suffer from seasonal allergies which, while they are now generally controlled, have seriously affected them at times, with severe bouts of coughing that can leave the sufferer weakened. In some patients, a respiratory allergy, uncomfortable at the best of times, can trigger asthma attacks which, if uncontrolled, can be life-threatening. All that could change...

Thanks in large part to your support and with additional research grants, Dr. McCusker and her team at the MUHC Research Institute have developed a peptide – a short chain of amino acids – that teaches the immune system to tolerate an allergen when it tries to set off an allergic reaction. "You reprogram the immune response at that moment," says Dr. McCusker, whose peptide has been patented and is in line for clinical trials that could begin in another five years.

With proper funding, the peptide could eventually be tested for use against even the most dangerous food allergies. "I can tell you, it would be a game-changer".



### WATERMELON BLUEBERRY YOGURT POPS

Stay cool and refreshed this summer with these easy-to-make, creamy yogurt pops. The hardest part is waiting for them to freeze!

#### **INGREDIENTS :**

2 cups 0% fat plain Greek yogurt
11/2 cups chopped seedless watermelon
1 cup fresh blueberries
1/3 cup liquid honey

#### **RECIPE :**

Place the yogurt, watermelon, blueberries and honey into a blender and puree until smooth. (For a chunkier version, pulse the mixture until desired texture.)

Fill eight 125 mL (4 oz) popsicle molds or paper cups with yogurt mixture. If using paper cups, cover top with foil and poke a wooden craft stick through the centre of each pop.

Place molds or cups on a flat surface in the freezer for at least 6 hours and up to 2 weeks.

This recipe was taken from the Health Canada web site

# Could It Be More Than Just Thirst?

Did you know the average adult is made of about 60 percent of water? At birth, babies are almost 78 percent. So fighting dehydration is a real concern, even in our industrialized country. Dehydration happens rapidly in the bodies of small children and can quickly become very serious. Here are some quick tips to help you detect dehydration and ways to treat it.

#### SIGNS OF DEHYDRATION IN CHILDREN

- Dry mouth or extreme thirst
- Fewer than six wet diapers a day for infants, or no urination for 6 hours in older children
- Looking or acting very tired or weak

You can treat mild dehydration at home by breastfeeding or bottle-feeding more often but for shorter time periods. You may need to give your child an oral rehydration solution until he can drink larger amounts of fluid without vomiting or passing stool. Whatever you do, do NOT give your child soft drinks, tea, juice, broth, or "sports drinks" like Gatorade, nor dairy products. Use medications for vomiting and diarrhea only if recommended by your doctor.

#### CALL YOUR DOCTOR RIGHT AWAY, OR 8-1-1 IF YOUR CHILD:

- Has a temperature over 101.3°F.
- Has been vomiting and having diarrhea for more than 12 hours.
- Hasn't urinated for 6 hours or more, or has dark or strong-smelling urine.
- · Can't drink even small amounts of liquid without vomiting.
- Cannot be soothed or is very irritable or restless.
- Seems unusually drowsy, listless, weak, or limp.
- Has dry, wrinkled, or pasty-looking skin, sunken-looking eyes, a very dry or sticky mouth, or cracked lips.

#### WHAT ABOUT YOURSELF?

Headache

You may be suffering from dehydration if you find yourself with:

Dry skin

- Dry mouth
   Decreased urine output
   Dizziness
  - Tired or sleepy

#### The key is to listen to your body because no one knows it better than you.

- If you are thirsty or are sweating profusely you need to replenish your body with water.
- A healthy person urinates seven to eight times each day, so if it's not your case, it means you're not drinking enough water.
- Drink as much water until your urine turns light yellow. Always bring a bottle of water with you during exercise or any physical activity.

With these tips at hand, we hope you and your family will enjoy summer to its fullest!

IT'S THE CARING FOR KIDS RADIOTHON wednesday, may 31, 2017 514-939-kids (5432) 6-9 AM / 3-7 PM

